



autism London

*providing support for those affected by
autism and Asperger's syndrome*

Bulletin

November - December



2006



autism London
Bi-Monthly Bulletin

1st Floor, 602 Chigwell Road
Woodford Bridge Essex, IG8 8AA

Please note we are unable to accept personal callers to the offices without an appointment.

HelpLine:

0845 6037954

Fax:

020 8504 5205

Email:

info@autismlondon.org.uk

Website:

www.autismlondon.org.uk

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Contributors:

Gordon Pownall, Dee King, Ethney Anderson, Monica Brewster,
Desmond Meldrum, Joe McDaniel, David Shamash, Louis Baworowski

We would welcome any feedback related to information printed in this publication.

The views and opinions expressed in Autism London's 'The Bulletin' are not necessarily those of the organisation.

Your donation and subscription as a Supporter enables Autism London to continue to provide its support services free of charge to those personally affected by Autism and Aspergers Syndrome

www.autismlondon.org.uk

All of our fact sheets have been recently updated and are now available for free download from our website.

If you know of a good service, event or opportunity for children or adults or those affected by Autism or Asperger's Syndrome why not let us know about it.

Email the information to us :-

info@autismlondon.org.uk

Dear Supporter,

Welcome to the final Bulletin of 2006. A very busy year for all at Autism London both at the Support Services and our residential home at Salisbury Road. Both Dee and Ethney have been covering a multitude of tasks including case work, covering the HelpLine as well as supporting Colin Guest develop funding applications.

Hopefully by the time you read this we will have a better idea of how things are progressing financially but as always, we need to ensure that we are making best use of our resources. Ethney is working closely with our Salisbury Road service to develop person-centred plans for the people who live there. Ethney has been working with Richard and Joe McDaniel who has written an article on person centred planning in this edition. Dee has been maintaining our HelpLine service and coordinating our ALAG meetings in Islington as well as organising her wedding so by the time you read this she will be married - our congratulations to her and her husband !

Desmond has taken over management of our membership database and continues to support the admin side of the work we do and Joan is of course kept very busy by us all.

We are sad to see the final book review by Louis Barowski. Louis has been a dedicated contributor to the Bulletin for the last 5 years and we will miss his thoughtful and well researched reviews. We wish him well in his new ventures, he will be missed.

As 2007 draws close, all of us at Autism London look forward with anticipation and excitement. We exist to provide support to those with Autism and Aspergers as well as those who themselves care and support individuals and we would love to know what kind of year you have had so please do let us know. If you have an article you would like to submit or know of an event or activity others may be interested, please let us know.

We will also be looking to recruit volunteers to the HelpLine towards the end of the year ready for going 'live' in January / February 2007 so if you feel that you can contribute some time to this very valued and much needed service, please get in touch through the HelpLine or the website for more information. We appreciate that you may not always get through the first time but please leave a message and one of our team will get back to you as soon as possible...



Best wishes to each of you...
Gordon...

Gordon Pownall
Senior Manager East London



Christmas and New Year

The Autism London HelpLine will be closed at 2.00pm Friday 22 December 2006 and re-open Monday 8 January 2006. Please do leave a message on our HelpLine as these will be checked regularly. Alternatively, you can send an email which will also be checked after the New Year holiday.

Support Service Update

Hello all supporters,

I hope you are all getting used to the autumn days, and the chillier nights. It's the time of the year to get your winter woollens out and crank up the central heating.

I have recently undertaken, along with other MCCH staff, Person Centred Planning Training. Currently Ethney and I are working closely with the Salisbury Rd staff team to implement this with the service users. This approach will really enable people to achieve some of their personal goals and this will in turn, enable each person to have more opportunity to explore new experiences in their life.

We have not been able to have parent carer support meetings for some time now due to limited resources, but we are hoping to resume this in the near future so please bear with us. We shall do our best to keep you informed and hope to meet with some of you early in the New Year, following enquiries recently.

The Autism London Asperger's support group is still running, please join us for a monthly discussion and light refreshments. We look forward to meeting with you and sharing your experiences, and topics of interest. Autism London would like our supporters to tell us how we can best support you, what you feel you need from us as an organisation. Please share your views with us so that we can try to make our service relevant and effective.

Well until next bulletin in the New Year, this is Dee signing off - keep warm...!

Dee King
Support Officer

THANK YOU..!

Who...?

To everyone who has very kindly given a little extra as a donation to support the work of Autism London, as well as paying their annual supporters membership.

In the New Year we should have a better idea of how successful our fundraising applications have been however the generous donations that have been made will go towards ensuring Autism London can continue to offer support to individuals, both adults and children and their families.

At a time of year when gifts are purchased for friends and loved ones, and personal budgets are strained, we do appreciate the extra contributions made to help support the work.

Again, on behalf of all the people supported by Autism London,
many thanks...

Gordon...

Hello again to all our members! It's hard to believe we're already approaching the end of 2006, it seems just a short while ago we were wishing you all a happy New Year!

I really do hope you've all had a good year and if you haven't.... ..it's not too late! Do something really special for someone.....or even for yourself.

We've just had our November ALAG meeting and guess what the topic was? Yes, 'Budgeting for Christmas!' It may seem a little late to start budgeting but it was still fun talking about what we should have done earlier in the year and how much better prepared we will be next year. We also had a great time sharing some wacky ideas for Christmas presents and discovering who received the funniest gift last year.

We've recently been contacted by another Aspergers group called Aspirations, who expressed an interest in meeting up for a social event with our ALAG members. So we're planning to invite them to come along to our meeting on the first Tuesday in December and if all goes well, arrange to meet up with them at a pub or restaurant over Christmas/New Year.

By the way, we have some Autism London Christmas cards for sale, so if you would like to order these you can phone, fax or email your orders through to us as soon as possible. See the website for more information...

I recently attended the excellent Learning Alliance Conference 'The 21st Century Perspective on Autism'. The main speaker at this conference (via satellite link) was the wonderful Lorna Wing - Psychiatrist, pioneer and parent of a daughter diagnosed with autism in the late fifties. Other speakers were Dr Richard Soppitt - Consultant Child Psychiatrist, Bill Colley - Consultant for local education authority and founder of Caledonia Training and Sandy Row - parent and author. The speakers examined the theory that there may be a higher prevalence of Autism in the 21st Century.

Some of you may have heard about the 'Every Disabled Child Matters' Campaign which has launched a report that spells out why the national childcare strategy is not working for disabled children and what needs to happen at a national and local level to prepare for the Childcare Act 2006. I would like to encourage you to join us in supporting this campaign for the rights of every disabled child. This campaign is supported by four national organisations working with disabled children and they want 10,000 supporters to sign up by December 2006. You can join now by logging on to: www.edcm.org.uk Please ask everyone you know to do the same.

Well the initial part of the training is completed - thanks to Joe McDaniel - and the Person Centred Approach is now being firmly established in our residential homes. Most of my time is spent implementing PCPs for the residents at Salisbury Road. This area of work is going really well and I'm pleased to report that PCP really is a practical tool that enables us to see each person in a positive light, support them to say what they want in their lives and help to plan for future needs.

We'll keep you informed about this important service development in future bulletins. That's all from me for the time being, but we do want to hear from you! Write in and let us know about your experiences, especially the ones that might be of help to others.

Ethney

The ALAG meetings will continue on the first Tuesday of each month between 6.30pm and 8.30pm at :-

**Highbury Baptist Church
40a Highbury Place
London N5 1QL**

Let us know how we can make these gatherings more useful – ideas or suggestions for guest speakers can be emailed to us or call us on the HelpLine...

TWO FESTIVALS OF LIGHTS IN WINTER

December is when the days become very short and the nights become long.

The Christians have a festival of lights called Christmas. The Jews have a festival of lights called Hanukkah which lasts for eight days. This festival commemorates the Macabean revolt against the Antiochus who was a Greek Syrian King.

He did not want to kill us but he wanted us to assimilate and tried to make us live like the Greeks. For instance he tried to prevent us from keeping Shabbat and wanted to force us to eat pork.

Exactly three years after the revolt started in 165 *BCE the temple was retaken by the Macabeas and there was only enough oil for one day. The oil lasted eight days.

We commemorate Hanukkah by lighting a candle for every night rising to eight candles on the eighth night and the last night of the festival.

In 2006 the festival is on from 15th December until 23rd December. In some places in North West London they have a menorah in the streets and we light the candles during Hanukkah on it.

**HAPPY CHRISTMAS TO OUR CHRISTIAN READERS AND
HAPPY HANUKKAH TO OUR JEWISH READERS OF
THE BULLETIN AND A HAPPY NEW YEAR 2007
FOR ALL OUR READERS.**

*BCE means before Christ or before the common era.

David Shamash is a regular contributor to The Bulletin...



News from Autism London's Residential Home at Salisbury Road

There has been a lot happening at the residential service, but the most significant of this is the Person Centred Planning for all service users that looks at the positive side of the service users' care plans. It also takes into consideration ways in which staff could help them with their aspirations and dreams.

Through this, staff are assessing the abilities of our service users take greater control of their lives with the support of specialist staff on a 24 hour basis.

After the PCP facilitators training, Richard Tucker, Mary Collison and Musefiu Lamidi with the assistance of Joe McDaniel, Ethney and Dee and the rest of the staff team at Salisbury Road have taken a giant step towards designing an autism specific person centred planning framework for the service users.

The meetings that we have had with the parents and families of these three service users have been fruitful and we have all worked towards implementing the plans.

Joe was happy with the progress we've made when we had our last meeting and made a few suggestions about how we could move to the next level. After we complete the PCP for the first three service users that we are currently working with we will be developing plans for the remaining service users.

Staff supported service users to attend the MCCH Conference on Employment and Activities in October. This was an enjoyable and informative day with lots of ideas for new ways of working.

Another good thing that has happened in the service that we would like to share with our colleagues is that 75% of the staff team are now NVQ qualified from Level 2 up to Level 4. Those who have completed level 2 are now working towards the level 3 and the 25% that have not yet completed the award are now working towards it.

Best wishes from all at Salisbury Road – have a great Christmas and New Year...

Seasonal Play Scheme Activities

22nd December

Magical Sleigh Ride and Santa's Grotto at Willows.

There will also be the usual farm activities to do and a show to watch here.

For more details see www.willowsfarm.com

Cost £20 Times £10am to 3pm.

28th December

Tobogganing at Hemel Ski Centre

We have booked the slope so we will be the only participants and will have a team of fully trained instructors with us.

Cost £20 Times 11am to 4pm

29th December

Beauty and the Beast Pantomime

Enter into the spirit of Christmas with a good old-fashioned pantomime.

Cost £23 Times 11am to 4pm.

It's going to be great fun contact us at 858 Finchley Road, London, NW11 6AB and join in!!

Any enquires Catherine Ely on 0208 458 3259 or catherineely@resourcesforautism.org.uk

Person Centred Planning

“Person Centred Planning used to be something counter-cultural, done by eccentric outsiders with coloured pens and strange ideas about having people in the room when decisions are being made about their lives. Now its government policy.”¹

Person Centred Planning is an important part of the Government's proposals for change for people with a learning disability as written in the white paper *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health, 2001). This was seen as a “watershed document” as it was the first government white paper on learning disability issues for thirty years and that it makes a clear and direct call for a change in opportunities for people with learning disabilities.

The strategy was produced by working groups of service users, carers, staff and leaders in the field of care, it calls for greater community involvement, greater choice about living arrangements and services that are flexible and accountable. Most importantly it embraces citizenship and everyday life as “the heart of the government's proposals” through four cardinal principles of *rights, choice, independence and inclusion*.²

It demanded an individualised approach to our work with people and identified person centred planning as a key tool for achieving this end. Person Centred Planning is now widely used by individuals, families, services and organisations across the country and not only for people with learning disability .

What is Person Centred Planning?

Person Centred Planning is a way of learning more about a person and what he or she wants in his or her life. In learning these things, it also finds out what help a person may need in order to get what they want.

With help from others (friends, family, staff), people are supported to take action. People usually make a plan because they would like to change their lives. (eg: moving house, finding a job, having more friends).

However, they sometimes make plans because their lives are changing and they wish to be prepared for this. (eg: their service, work or health changes or they lose family or friends)

How is Person Centred Planning Different?

Many connected to the profession argue that this is either “something we already do...” or if they understand it may negatively argue that it is “not possible” due to the person's abilities, limited resources or other reasons.

What really should be said is that Person Centred Planning can be “uncomfortable” because it inherently challenges the way services have traditionally done things.

¹ Kilbane, Jackie; Routledge, Martin; Ritchie, Pete; Sanderson, Helen: *People Plans and Practicalities- Achieving Change Through Person Centred Planning*. published by SHS Trust, Edinburgh, 2003, back cover notes.

² Department of Health; *Valuing People- A New Strategy for Learning Disability for the 21st Century*. Published by the Department of Health, 2001, pg.3.

Person Centred Planning is different from service planning because...

- It is about a person and his or her life. The person is in charge. Other people and services are there to help, not control. It focuses on an individual. Person Centred Planning does not look at people collectively or in terms of a service group.
- To create the right situation for this to happen can be challenging to us (paid staff, clinical professionals and families) as traditionally we have had the role of making decisions for people, rather than really learning what a person wants from his or her life.
- It's positive!...and celebrates what people enjoy, are good at and feel to be important. It also talks about support needs, personal health and staying safe...but in a way that helps people get more from life rather than being held back or denied opportunities.
- It's inclusive. The person invites who he or she wants to be involved. Family, friends and paid people are to be real partners together and take action. It also looks to use the community as well as services for opportunities.

Person Centred Planning in MCCH

Person Centred Planning is happening across MCCH's services. Many people who have made plans have changed their home, have improved contact with their families and have made new friends.

Others have tried new activities and have increased confidence in their personal skills and decision making. This has led to services changing their work practices and improving in how they support people.

Interest in Person Centred Planning is growing, with new planning circles starting in MCCH's East London services and Autism London's service at Salisbury Road.

I look forward to talking more with people about person centred planning and hope that more would like to get involved... for either themselves or to support each other in thinking about the future.

Best wishes,

Joe McDaniel

Joe McDaniel is employed by MCCH as a Consultant in Person Centred Approaches. He is Joint Winner of the MCCH Employee of the Year 2006 and is currently working closely with our residential home at Salisbury Road, Leyton developing Person Centred Planning with those who live there.

Supporters' Forum

Notices & Conferences

Research – NAS

The National Autistic Society are doing research into people with Autism coming from Ethnic back grounds. Development Officer Prithvi Perapa of the BME project is conducting this research. For further information contact Prithvi Perapa on: 0207 704 3806

Supporting Asperger Families in Essex – One day conference

A day examining a range of practice in the delivery of social and communication skills including input from young people with Aspergers. Chelmsford venue Saturday 9 December 10.00am – 4.30pm.

For more information contact SAFE, 01621 842734.

Dance/Movement Therapy

Details: A weekly class at Expressions studio in North London called Hop Step Jump.

The class is a dance and movement therapy session for children with autism.

For more information about the clubs please contact Erin McMahon on: 07968 778 757 or email: emcmahon@lambeth.gov.uk

Anger and Anxiety in ASD

A Day run on 30 November by Bromley Autistic Trust. For more information contact joparker@brmleyautistictrust.co.uk

Volunteers needed

Could you offer some spare time, maybe 3 or 4 hours each week to staff the Autism London HelpLine ? Our offices are in East London and we offer reimbursement of travelling expenses and training for those selected.

For more information and an application, please leave your details on our HelpLine – **0845 603 7654**

Cinema Exhibitors' Association Card Website.

Details : This is a national card that can be used to verify that the holder is entitled to one free ticket for a person accompanying them to the cinema. To apply for the card, you will need to meet one or more of the following criteria:

- a) Be in receipt of the disability living allowance or attendance allowance.
- b) Be a registered blind person.
- c) Be a holder of a disabled person's rail card.

Go to their website for more information and an application form <http://www.ceacard.co.uk/>

BOOKS

By Louis Baworowski

Louis Baworowski's career has included social work, academic research and journalism. For several years, he also worked as a volunteer writer for the National Autistic Society, preparing abstracts (summaries) of scientific and general articles on ASD for the Society's database. He is the father of Osian, a 25 year-old with autism. The aim of this regular column is to cover works of interest to readers of *Autism London Bulletin* irrespective of publication date. Where non UK-English spellings appear in titles, names or quotations, it is due to the spellings employed in the relevant sources.

Michael Blastland, *Joe: The Only Boy in the World* (London: Profile Books, 2006) ISBN 1-86197-961-4

This book is a portrayal of the author's son, Joe, as well as Michael Blastland's own mixed feelings about his child who, "Nowadays...lives with the label 'autistic'...a label that's best put aside before getting to know him (ps. 2-3). It is, however, in substantial part also an exploration of various *themes*. With references to the ideas of psychologists, philosophers and others, it attempts to interpret the way that people with Joe's problems experience and relate to the world. For this reason, its chapters bear titles such as, "Obsession," "Language," "Self-consciousness," "Innocence" and "Meaning."

Ruth Rendell, who is quoted on the cover, hails the work as, "No less than a voyage into the deep places of the human spirit and a vision of what lies beneath conventional notions of sanity and aberration." And on an inside flap of the bookjacket, we are informed that, through his very strangeness, Joe is someone who, "makes normality luminous." Such fanfare is overblown. Speculation about the quality of awareness of people who lack adequate means of communication, do not necessarily result in certainties. It is much easier to remember this book's questions than its answers, "visionary" or otherwise. The reader who is already familiar with frequently discussed aspects of autism, is, in the main, unlikely to find himself especially surprised, or have his views transformed, by this study. However, the fact that it contains no ground-breaking "revelations" does not, of course, imply that it fails as a description of Joe, or that it will not be of interest those who enjoy reading about individuals with special needs and their disabilities.

The Blastlands have had their share of upsets and embarrassments – only some of which are hilarious, even in retrospect. There was the occasion when the father lost sight of his son for a few moments in a crowded DIY store, only to find him with his trousers around his ankles, happily sitting on a display toilet relieving himself: "Please God...let it not be on CCTV," prays the father in a sweat (p. 126). Another incident concerned a stranger's toddler in a pram, while Joe and his father were standing in a public building, waiting for a lift. Joe punched the child, transfixing both the toddler's mother and Joe's father with shock. The father's distraught attempts at explanation were accepted by the mother, but with a marked absence of enthusiasm as can be imagined. (ps. 148-9)

Principally, however, what gives this book its specific character are the author's intellectual ruminations, combined with his ambivalence and anxieties. Some of these, for me at least, made for distressing reading, because they depersonalise and reify his son – even if, as Blastland has it, this is due to the objective nature of the boy's condition, rather than some fault of parental judgment. According to the father: "What we see when peering into... [Joe's] mental machinery [dad's term] is a child possibly lacking almost all the philosopher's traditional definitions of what it is to be human" (ps. 6-7). Later we read: "...lack of self-consciousness and lack of awareness of others can indeed run together...for the time being this doubt about Joe's capacity for one of the core attributes of humanity rattles me to the bones. I cannot write about it without seeing again his blue-grey eyes looking into mine with a gaze that seems to scour my soul. And yet I've wondered if he isn't just bewitched by the reflecting light, perhaps the light of his own image on their surface, so that even what appears deep is shallow. Is he self-conscious or not? If he has some self-consciousness, how much?" (p. 120)

To be fair, the father is not without love for his son, but rather is conflicted in his thoughts and feelings. He “cried helplessly” when he was moved by the sight of Joe under an anaesthetic (p. 166). For myself, I regard Joe’s humanity as self-evident and find it almost incomprehensible that anyone should be so dominated by the abstractions of science, pseudo-science (scientism) or philosophy, as to prevent him from relating to his child in a natural fashion, without tormented glances over his shoulder to see what the “experts” might be saying. I would, in any case, not wish to fixate on any putative frontier of what is or is not “human” as a basis for deciding what we should value or care for. This is both unnecessarily limiting and too susceptible to ideological manipulation. The Nazis, for instance, classed a whole part of mankind as subhuman and used this as justification for genocide and other mass killings. The “unworthy” included not only all “non-Aryans” but also the mentally handicapped. I prefer Schweitzer’s notion of reverence for life, the Buddhist ideal of compassion for all sentient beings or a simple heartfelt response as a basis for ethical behaviour.

A Farewell...

This month marks five years of my reviews in *Autism London Bulletin* and I feel it is time for me to move on. Accordingly this is the last of my “Books” columns in this newsletter. Since December 2001, 58 of my reviews have been printed in the newsletter, 23 of which have been reviews of personal accounts by people on the autistic spectrum or their parents. I have used this column to promote understanding, by describing the lives and experiences of people with an ASD diagnosis whom I have read about, as well as sharing other information and ideas that I came across in the books reviewed and elsewhere.

People with autism and their family contexts differ enormously, so that the extent to which any one story mirrors or speaks to the condition of the individual reader may be limited. This said, familiarity with a *range* of biographies cannot but widen appreciation of the extremely unusual experiences which can occur in autism, giving us a greater store of ideas to draw upon when thinking about our own child. It is not every day, for instance, that we learn about university instructors who are capable of teaching, but have difficulty finding their way to their class (Liane Holliday Willey, December 01 issue); about individuals who need to move in order to experience their own bodies or “presence” (Tito Mukhopadhyay, April 03); about people who may not “really” recognise their parents because they think that they might merely be encountering replicas of them (Gunilla Gerland, October 03); or the person with synaesthesia who, on hearing a wood-pigeon, would see sharp spikes of a brilliant purple/grey colour while at the same time feeling needle-sharp spikes with his hands! (Mark Hewetson, December 05)

Given the heterogeneous nature of ASD, and the colossal differences between individuals with the diagnosis, it is almost nonsensical to generalise about treatments. Some approaches, however, are more reputable than others, ABA (Applied Behaviour Analysis) and Dr. Stanley Greenspan’s Floor Time among them (see my reviews of February, April and June 04, as well as December 05). There is also wide agreement that early intervention, ideally before the age of four, and sustained teaching and training programmes, hold out the best or even *only* hope of dramatic progress – not to say a far more interesting life! – for both child and parents. The “do nothing” stance, criticised by Professor Feuerstein and his colleagues as well as by Professor Ritvo (see the April 03 and October 06 issues) *has nothing at all to recommend it.*

It is very rare indeed to come across a book that can open some radically new vista for parents considering their options, but one such is T. Dowty and K. Cowlshaw’s *Home Educating Our Autistic Spectrum Children*, reviewed in the October 02 issue. For some families, home teaching is a real, practical and viable alternative to harrowing school experiences.

Our thanks go to Louis for his much valued contribution to Autism London’s Bulletin over the years and our best wishes to him for the future from all staff and readers